

Report to the Clark County Partnerships for Youth Transition Steering Committee

Results from Youth and Family Focus Groups and Service Provider Questionnaires

May 6, 2003

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Acknowledgements

We wish to express our thanks to the people whose efforts made this report possible, including Diana Burger and DeDe Sieler of Clark County Department of Community Services, who facilitated recruitment; Denise Martino and Jeanne Mack of Youth House, who provided space for youth focus groups; Mary Jadwisiak of the Community Empowerment Project, who graciously made space available –and provided refreshments!- for moderator meetings; and the Partnerships for Youth Transition Steering Committee, who provided encouragement and feedback on who to ask and how to ask it, as well as recruiting staff within their own agencies to complete provider questionnaires. We would especially like to thank the caregivers, youth and service providers who took part in focus groups or took the time to respond to the questionnaire.



Melanie, Erick, Jimmy and Drew at our team analysis meeting, 4/18/03.

Executive Summary

As part of the strategic planning process for the Clark County Partnerships for Youth Transition Project, researchers from the Regional Research Institute for Human Services (RRI) at Portland State University organized, conducted and analyzed results of a brief series of focus groups with youth of transition age, and with family members of youth of transition age. The research team included four youth and two family member moderators/evaluators, all with direct experience with mental health and other services. A separate, short survey of Clark County service providers was also developed and given out to a wide range of agencies and institutions.

Twelve youth and ten family members took part in seven separate focus groups over the course of single week in early April 2003. All had been involved, or had a child involved, in mental health services; some had involvement with juvenile justice, special education, drug or alcohol treatment, or vocational rehabilitation services. Focus groups were tape recorded, but not transcribed. Moderators' notes and paraphrased comments from attendees were analyzed and reviewed by the evaluation team as a whole for emergent themes and unique insights. Twenty-four service providers returned completed surveys over a three-week time span from mid-April to early May 2003; survey responses were grouped by question for analysis.

These efforts were meant to provide the project Steering Committee with current 'word from the street' about consumer and provider views of what works, what doesn't work, and what could work in regards to supporting youth with emotional or behavioral challenges, and their families, as these young people move into adulthood. Results and implications for the Partnerships for Youth Transition Project follow.

Focus Group Results

- ❖ What's working? What should we keep or do more of? Focus group members identified...
 - The presence of supportive personal relationships for youth with caring, respectful adults, including mentors, extended family members, counselors, probation officers, and others.
 - The use of out-of-office, community-based settings for services and support.
 - The support and individualized service offered by the wraparound/ITC¹ process.
 - Striving for ongoing collaboration and communication between agencies, and coordination of supports and services.
 - Having the right diagnosis, and the right intervention(s), including medication, when needed.
 - The availability of (some) opportunities to learn life skills, especially independent living and job-related ones.
 - Provision of family support, education and advocacy.
 - Seeing the family as a whole.
 - Flexible funds, when they can be accessed.

¹ Individualized and Tailored Care, a term for wraparound services in Washington State.

- ❖ What isn't working? What should we do less of or not at all? Youth and family members spoke of...
 - At times, a lack of respect from service providers.
 - Gaps in services across life domains.
 - Lack of access to services due to strict eligibility rules, inadequate financing, and lack of information about availability.
 - Sloppy or rushed assessments leading to misdiagnoses and poorly-fitting interventions.
 - Inadequate knowledge of and training about mental illness and treatment of youth with emotional or behavioral difficulties
 - A lack of collaboration and communication between providers, families and youth
- ❖ What could work? What else should transition services and supports include? Young people and caregivers suggested...
 - Improve collaboration and communication.
 - Aim for proactive, not just reactive, approaches.
 - Develop peer mentoring with and for youth.
 - Have counselors stay with the youth and his or her family through the transition to adult services.
 - Provide ITC for each person going through transition.
 - Provide more life skills training in communication and other skills.
 - Increase youth involvement in the service system and in their own care.
 - Increase awareness of services.
 - Include positive recreational options for youth.
 - Start a youth mental health court, building on Clark County's experience with adult mental health court.

Provider Questionnaire Results

- ❖ Service capacity exists among individual agencies; however, while services may be available, they continue to function in a fragmented manner. Thus, providers identified a need for improved coordination and collaboration in service delivery.
- ❖ While individual agencies' services may address one or more of the TIP² transition domains, more services are needed to completely address these domains (which include housing, employment, education, and community life functioning).
- ❖ With a few exceptions, when youth turn 18 providers described a serious lack of consistent, well-planned and coordinated, and comprehensive transition services.
- ❖ Policy and practice barriers are substantial:
 - services are still largely fragmented and categorical;
 - policies or resources to provide continuity of care and long-term follow-up are unclear or very limited;

² Refers to the Transition to Independence Process (TIP) model (see Clark & Foster-Johnson, 1996).

- different services' eligibility requirements, especially age- and income-related, vary a great deal, and may leave some of the most needy youth out (parallel to health care system leaving out the 'working poor');
 - certain eligibility requirements exclude youth from receiving the services they need the most (i.e., substance abuse makes Medicaid unavailable); and
 - some agencies reported having policies that prevent or disallow adult providers from working with youth.
- ❖ Funding barriers aren't going away; providers reported:
 - a general lack of funding for youth and transition services;
 - a lack of flexibility in funding services for youth; and
 - flexible funding is difficult to obtain.
 - ❖ Youth and family involvement in service planning, decision-making and provision varies, but is often present.
 - Many providers reported that families and youth have a significant voice in planning their own services
 - Some providers described a more significant role in strategic planning, consumer/family advisory board input, etc.
 - One agency reported involvement of youth as service providers (peer mentors)
 - ❖ In other comments, the need to address the key TIP domains was asserted; the need to involve youth as soon as possible and as often as possible, in more than token ways, was advocated for; and a desire to include extended family members as much as possible was expressed.

Implications for the Strategic Planning Process

- ❖ Collaborative, coordinated services are valued and needed throughout the transition years.
- ❖ Services that address key TIP transition domains need to be completely developed and linked.
- ❖ RESPECT is key in engaging youth and family members.
- ❖ The participation of youth and family members at all levels of planning and providing services—individual, program, and system—is essential.
- ❖ Eligibility criteria can act as barriers and be confusing when soliciting services.
- ❖ Families, youth, and providers all want flexible, non-traditional services.
- ❖ Staying true to key features of the TIP/TACT models (as envisioned in Clark County) will match youth, family and provider preferences.
- ❖ Additional efforts should be made to include the views of culturally diverse youth and family members, as well as a wider age range of youth.

Introduction: Overview of what we did and who we are

Overview

As part of the strategic planning process for the Clark County Partnerships for Youth Transition (PYT) project, the Portland State University-based evaluation team took the lead in developing and conducting a brief series of focus groups with local youth, and with families of youth, with emotional or behavioral difficulties. The purpose of these group discussions, held over the course of one week in early April, 2003, was to gather current information from the community about consumers' experiences with transition-relevant mental health, substance abuse, special education and other services in Clark County. Our goal is to provide the PYT Steering Committee with current insight into existing –or ideal-- youth transition services; in brief, to let program planners know *what works, what doesn't work, and what could work*.

In addition to focus group discussions, a non-random, purposive survey of Clark County social service and education agencies was undertaken to gather information on existing services, gaps in those services, barriers to meeting the needs of youth, and about ways in which transition-aged youth and their families can be better included and served.

This report presents results from both activities. For convenience and clarity, we have described research methods and findings for each activity separately. The final section of the report summarizes findings from both groups; it also suggests some implications of what we learned for the PYT strategic planning process. Whenever possible, we have included the words of youth, family members, or providers themselves. We have been careful to protect the confidentiality of all focus group participants in particular; thus, no identifying details have been included when their comments are cited.

Who we are

In keeping with system of care values around youth and family member involvement, four youth and two family evaluators were hired by the Regional Research Institute³. They were trained by the project manager, served as moderators for the four youth and three family focus groups that provided information for this report, assisted in identifying key themes from these focus groups, and presented findings to the Steering Committee. As project process and outcome evaluation activities unfold, these family and youth evaluators will continue to play essential roles as interviewers and as contributors to future analyses.

The two lead authors of this report, Lyn Gordon and Mike Pullmann, are full-time researchers at Portland State University. Lyn is Project Manager for the PYT evaluation; he is a mental health consumer (diagnosed with bipolar disorder in the late 1970's), a social worker and a parent of youth who have received mental health services. Mike is the evaluation's Statistical Consultant, and is very familiar with Clark County services through his management of the Clark County System of Care Evaluation at PSU. Co-authors and focus group moderators Jimmy Cunningham, Brenda Dalke, Melanie Green, Erick Jadwisiak,

³ See the report *Blamed and Ashamed* (Federation of Families for Children's Mental Health and Keys for Networking, 2001) for another example of direct youth and family member involvement in research.

Sondra Martin and Drew Stapleton all contributed to the identification of key themes and important points for inclusion in the report. Jimmy, Melanie, Erick and Drew are all young adults with significant personal involvement with services in Clark County. Brenda, like Lyn, is a mental health consumer; she is also a parent of a young adult who has received mental health services, and is a parent advocate as well. Sondra is a parent trainer with the Community Empowerment Project. We met for initial moderator training in late March 2003, and each of us took part as moderator of at least one of the family or youth focus groups (with the exception of Mike, who was present outside the room to support most youth groups, but did not moderate, by design).

Focus Group methods and results: How we did it, and what youth and family members told us

Focus Group methods: How we did it

Planning for youth and family focus groups began in February 2003, with development of draft questions at Steering Committee meetings and preparation of an application for the Human Subjects Research Review Committee (HSRRC) at Portland State University. As it turned out, approval of the application was unexpectedly slow in coming, resulting in re-scheduling of an April 3rd youth focus group to April 10th.

Youth and family members were recruited through distribution of informational flyers throughout the county by Steering Committee members and family organizations, as well as through word of mouth. Potential participants were invited to call the Department of Community Services to get more information and to sign up for a given group. DCS staff asked basic screening questions, since we needed youth who (or family members whose children) were receiving or had received mental health services. Staff answered callers' initial questions, took down contact information in order to send a letter of invitation (found in Appendix A), and scheduled a focus group time that was most convenient for the youth or family member.

At the groups, all participants were asked to sign an informed consent form, reproduced in Appendix B, which included permission to audiotape the discussion. We explained that taping would be helpful in making sure their ideas would be heard. Great care was taken to assure each member that confidentiality would be strictly upheld, that no one's name would be tied to any comment or idea in the report, and that tapes would be erased immediately after this report was prepared. Tapes were not transcribed, but were listened to during the analysis process to supplement and clarify moderator's notes.

Each group member was given a copy of questions for the group (please see Appendix C) that they were free to write their comments on during the discussion. The questions provided structure, but did not need to be answered in any particular order. Food (sandwiches or pizza, cookies, and beverages) was provided at each group, and each group member was given a \$15 gift certificate at the end of the group as compensation for their time. Groups ranged in length from 45 minutes to over 90 minutes; in all cases, the family groups ran longer than the youth groups.

Group discussions were generally lively, sometimes emotional, and rich with the direct, lived experience of the young people and adult caregivers who took part. One limitation of the groups was their relative lack of diversity: only one father took part; just three young women attended; and all but one (an Hispanic caregiver) were European American in ethnicity. Groups were also occasionally challenging to moderate, which relates to another limitation. As could be expected from a gathering of youth with emotional or behavioral difficulties, those difficulties at times surfaced during the youth focus groups; despite Erick, Jimmy, Drew and Melanie's creative efforts, some young people's contributions were cut short by interruptions and disruptive behavior of their peers. In some family member groups, on the other hand, strong emotions around especially negative experiences may have contributed to under-reporting of helpful (or ideal) services and supports. Another limitation of the groups was the lack of older youth (21 years+), other than the presence of Melanie and Erick as moderators. A strength of the focus groups as a whole is the range of services, and of experiences --good, bad, and mixed-- with those services reported by group members. Although numbers were not large (we had hoped for about 5 members for each group), this breadth of experience makes the usefulness of the results that follow more likely.

Table 1 shows when and where groups were held, who moderated, the number of youth or family members who were there, and the types of services they (or their child) were or had been involved with.

Table 1: Family Member and Youth Focus Groups, April 2003

Date/Time/Location (type)	Moderators	# of Youth or Family Members (total = 22)	Types of services involved with*
4/5/03 12-1:30pm Luepke Ctr. (family)	Brenda & Lyn	5	MH, JJ, AD, SPED
4/5/03 12-1:30pm Luepke Ctr. (youth, co-ed)	Erick & Drew	5	MH, JJ
4/8/03 4:30-6:00pm Youth House (youth, "guys only")	Jimmy & Erick	1	MH, SPED, JJ
4/8/03 6:00-7:30pm Luepke Ctr. (family)	Brenda & Lyn	3	MH, SPED, JJ
4/10/03 4:30-6:00pm Youth House (youth, "girls only")	Melanie & Drew	2	MH, AD, VR
4/10/03 12:15-1:45pm Clark County Public Service Center (family)	Sondra & Lyn	2	MH, JJ
4/11/03 12-1:30pm Youth House (youth, co-ed)	Jimmy & Erick	4	MH, SPED, AD
*MH = Mental Health; JJ = Juvenile Justice; AD = Alcohol/Drug; SPED = Special Education; VR = Vocational Rehabilitation			

Following completion of the groups, Lyn and Mike prepared an initial listing of points raised by individual group members by listening to the tape recordings, transcribing illustrative quotes, and reviewing notes from each group. The entire team –youth, family member and professional evaluators alike-- then met as a group to confirm, amend and expand on the initial analysis, based on what each moderator had heard and experienced. The focus group findings that follow were distilled from that discussion, part of which is captured in the photograph on this report's Acknowledgements page.

Focus Group results: What youth and family members told us

What's working? What should we keep, or do more of?

We took a strengths-based approach to our exploration of consumer experiences, making conscious efforts to draw out the positive experiences young people and caregivers may have had with services and supports. A promising number of themes emerged.

First, the value of ***supportive personal relationships for youth with caring, respectful adults***, like mentors, counselors, probation officers, youth pastors, teachers or family members, came up in almost every focus group's discussion. Youth spoke of these kinds of relationships in comments like "[services] ***helped because you felt like people actually wanted to be part of your family***"; and "[they] ***worked because they don't blame you for everything, they actually listen to you***. Speaking of the unconditional commitment his Connections counselor had shown him, one young man described his experience while in an out-of-state placement: "***My counselor flew up three times just to see me. It was awesome!***" Another youth referred to the support offered by a probation counselor, who "***gave me enough rope to hang myself, then when I screwed up, the support to redeem myself***." Family members also appreciated the "extra mile" efforts of caring providers and community mentors greatly, and believed that adults' provision of activities like fishing, going to ball games, and working on creative hands-on activities (like creating a quilt or building bird houses) had helped their children greatly.

An ***out-of-office, community-based setting for support*** was endorsed overwhelmingly by both parents and youth. As one mother stated, "***I want them to come in the home, because it's like, our own environment. My son won't go in to counseling, he refuses [to go to an office]...so that way the whole family can participate***." Some youth and family participants mentioned church-related people and activities as particularly helpful, while others brought up this point while discussing community-based mentoring activities.

Also frequently mentioned as helpful was ***the wraparound/ITC process***. Both youth and family members valued the support and individualized services offered by wraparound teams. A youth focus group member summed up his thoughts around wraparound meetings simply: "***They work***." A family member went into more detail:

One of the things that I think I've found the most successful is when a group of people, ... like psychologists, counselors, mentors, that type of thing, all work together as a wraparound team. My child has had that kind of service since he was in elementary school...I really see the value of teams working together...it's a more productive, well-rounded approach.

Further explanation of why wraparound works was offered by another mother:

I think the wraparound service is one of the best things to happen in mental health, ever. Because it's not just on the parent; you don't have to come up with all the answers; they're so many reasons why this works. I think that anybody who has a child with problems should have a wraparound team, period. I think they're very much needed.

The helpfulness, when it happens, of **ongoing collaboration and communication between agencies, and coordination of supports and services** was mentioned several times. When different agencies and systems collaborate, communicate with one another, and offer coordinated services (the approach used by the Connections program was given as an example more than once), families and youth reported feeling supported.

Having the right diagnosis, and the right medication (when needed), was seen as very helpful by many family members and some youth. As one parent reported, *"It's been a real struggle...until we got the right diagnosis."*

Both youth and families appreciated **opportunities to learn life skills, especially independent living and job-related ones**. Training provided through Job Corps was praised, but not universally (see below); similarly, a program of the Department of Vocational Rehabilitation called 'Mission Possible' was mentioned as being supportive and encouraging, but not having led to actual employment. One young woman mentioned a particular class at her high school that helped her greatly with problem-solving skills.

Provision of support for families was acknowledged by many family member participants. Sometimes such support is provided as part of involvement with a particular agency; as one parent described:

One of the other positive services...is having parent support people. Like Catholic Community Services, for example, has been a real valuable service for me; I've been facing some issues with my kids that I'm not totally equipped for, and they've come along and they've said, "#1, we care, and we understand, and #2, here are some resources, and #3, I'm gonna sit here and help you fill out the paperwork for these resources.

Other family members spoke of positive experiences with Parent Partners, family members who have been trained through the Community Empowerment Project to support and advocate for other parents and caregivers. Still others spoke warmly of respite care they had received, or other ‘non-traditional’ help they had been offered.

Family members also frequently brought up the helpfulness of ***seeing the family as a whole***. For some, this meant being offered family therapy; for all, it meant recognizing the effect that one child’s problems have on other family members. As one family member put it, ***"See my family as a whole; it's a unit. One part impacts the other."*** Sondra summed up the experience of group members at the discussion she moderated in this way: ***"The family itself is a whole unit, and every person in there is a piece of that unit. You can't really work with just one piece of that unit and expect that the whole family's going to start working great."***

Finally, ***Flexible funds*** were mentioned as useful by a few family members and youth. Providers’ ability to respond quickly to a young person’s need for transportation, food or other incidental expenses made a difference for some. More families and youth reported not having access to or being denied flexible funding, however.

What’s not working? What should we do less of, or not at all?

Understandably, focus group members had much to say about problems they had encountered with services and institutions. Both youth and family members’ strongest complaints centered around ***lack of respect from service providers***. Youth objected to professionals telling them what to do, rather than giving them choices. As one young man described,

I had a say in my services, but I still felt like I was being forced around...they didn’t give me any options; they talked to me about my childhood, and how my childhood affects me. They don’t really seem to care. It doesn’t seem to work for me.

Other youth spoke of their distaste for therapists who “just talked” or didn’t meet them at their level. Still others felt they were not really given a say in making decisions that affected them; as Jimmy summed up during one of the groups he moderated, ***"We should always have a say in what happens in our own lives."***

While family members who had been involved with wraparound services felt respected by those providers, others who had been involved with other community agencies and institutions spoke of their deep feelings of mistrust that had developed as a result of breaches of confidentiality or from denial of sorely-needed services. Especially when their child’s or family’s difficulties had led to involvement with the police, child welfare services, or

juvenile justice, parents shared the sentiments of one mother who stated, ***“I felt very unsafe, very threatened.”***

Gaps in services were identified during the focus groups. Several youth were particularly vocal about the lack of accessible job skills training and actual employment opportunities; one felt that ***“Job Corps was a joke,”*** and that employers were not flexible enough. The lack of qualified --and high quality--psychologists and psychiatrists came up in two of the three family member groups. One family group’s discussion brought out the inadequacy of services available for traumatized --and sometimes sexually reactive-- youth. Both family members and youth reported that emergency care and crisis services are poor in Clark County. In the words of one parent,

There’s kind of a real big hole in crisis intervention, immediate emergency crisis intervention...Pretty much the response I’ve gotten is either he’s got to go to the hospital and sit for four hours to be evaluated, and they may or may not keep him, or you’ve got to call 911, and then I finally got a hold of some emergent services, and they put a call in here and a call in there, and we’re talkin’ hours and hours have gone by.

Realistic, appropriate options for living situations were perceived as limited by both young people and caregivers. Drug and alcohol treatment options were described in mixed terms; one youth talked of her unhappiness with the group treatment approach she had been ‘stuck with’ when involved with one provider, voicing a preference for her current individual outpatient treatment instead. A potentially helpful community resource and source of information for families and youth, the Family Resource Centers located throughout Clark County, were seen as understaffed and underfunded. Finally, shortages of qualified foster care and respite care providers were mentioned by some family members as well.

Another frequently-cited concern surfaced around the ***lack of access to services due to strict eligibility rules, inadequate financing, and lack of information***. Several youth and families spoke of services that were difficult to access, and of the differing requirements once age 18 is reached that put up additional barriers. Parents reported being told that they could only change counselors once a year, regardless of a poor fit of the therapist with their child’s needs. Parents also spoke of services that ***“can leave you hanging, sometimes,”*** due to eligibility and timeline policies (e.g., services are sometimes not allowed to overlap between agencies when a transition period would be appropriate). Youth and families alike spoke of difficulty even finding out about services; as one parent reported,

A lot of these resources have only become available because you find out through other parents, or something you have to find out and research on your own. And it gets kind of overwhelming sometimes.

Tight budgets were seen as the ‘bottom line’ around access to services: a parent’s comment that ***“Money always gets in the way,”*** sums up the experience of several families and youth.

Family members in particular identified ***sloppy or rushed assessments leading to misdiagnoses and poorly-fitting interventions*** as a concern. In one parent's words,

The assessments that they do just aren't effective. My [child, now a young adult], I don't know how many diagnoses he's gone through since he was five, I don't know how many medications he's been on, I don't know how many people have put him on different medications.

Some, but not all, county schools were called to task for inadequate (and at times out of compliance) Individualized Education Plan (IEP) assessments, planning, and follow-through.

Inadequate knowledge of and training about mental illness and treatment of youth with mental health diagnoses on the part of counselors, police, school staff, and youth and family members themselves was raised several times. Police were singled out as seemingly ignorant of state laws that pertain to youth with mental health concerns and/or developmental disabilities, as well as poorly-trained in interacting with these youth. Teachers and school staff were also mentioned several times as being either too harried, too burnt out, or lacking in proper training to sensitively respond to youth with emotional or behavioral difficulties.

A final theme, the ***lack of collaboration and communication between providers, families and youth*** surfaced in several groups. In one example, a mother described her perception in this way:

Between community services and the school, there's like no communication whatsoever. It's a one way street. And the only time, it seems, that the school cares about what kind of services my son's receiving has to do with the truancy board.

What would work? What changes should we make, and what dreams should we strive for?

Answers to this area of questioning came in different ways from different focus groups. Some young people and caregivers responded to variations on the question, "What one thing would you change to make things better?" Some re-stated earlier positive points into features of 'the ideal system.' And some arose out of the give-and-take of the focus group process itself, where one idea sparks another, which leads to yet another, and so on. The evaluation team identified the common themes and unique ideas that follow.

Extending on the discussion of a key strength and weakness in the current service system, youth and family members spoke to the ideal of ***improving collaboration and communication between providers, agencies and support systems***. Youth and

caregivers were well aware of both the benefits of well-coordinated services and the drawbacks of poorly-coordinated ones.

Family members gave special emphasis to the goals of ***aiming for proactive, not just reactive approaches, and including an emphasis on health, nutrition and fitness into interventions.*** One parent advocated for such a value, saying “*It would be nice if people could request services whether they’ve committed a crime or had a serious mental illness, or whatever the case may be. It’s like preventative, like we were saying, proactive as opposed to reactive...*”; she realistically added, “*And I realize that there’s not a lot of funds in that area.*” Other parents spoke of their belief that their children’s development into adulthood had been, or would have been, enhanced by incorporating an emphasis on healthy food and exercise, and that this would be worthwhile to keep in mind as well.

Flowing out of discussion of the value of adult mentors, family members suggested ***developing ‘peer partners’ with and for youth.*** This was envisioned as perhaps a youth parallel to existing ‘parent partner’ efforts, or else as a kind of ‘big brother or sister who’s been there’ approach.

Recognizing their own struggles with the change from the child to the adult service system, several youth and caregivers alike wanted to ***have counselors stay with the youth and his or her family through the post-18 transition, or stay on to help with the transition to an adult counselor.***

In harmony with the TIP and TACT models, family members in particular believe that an ideal system would ***provide Individualized and Tailored Care for each person going through transition.*** Both youth and caregivers described generally positive experiences with this collaborative, strengths-based, youth- and family-centered approach to meeting their needs.

Both youth and family members called for ***providing more life skills training in communication and other skills,*** building on real-world experience. One mother expressed this common vision in a unique way:

Along the lines of thinking of something that’s proactive...some sort of job skills training, some of these employers in the county could be encouraged to take some of these 16, 17 and 18 year olds and benefit from that financially, like work study with us going to school, y’know, the government pays people to employ us so that we can go to school. A situation like that where these young [people] have an opportunity to...learn a skill, learn a trade. Once you have that ability, that skill, you can put a roof over your head and food on the table no matter where you are.

Young adults spoke strongly of the value of ***increasing youth involvement in the service system and in their own care.*** As Jimmy put it, in his dual role as participant and moderator of the smallest focus group, *"All I needed was a little nudge from behind...give me the choices, then let me make that choice."*

Youth and family members addressed the need to --and ways to-- ***increase awareness of services.*** Youth suggested concerted advertising efforts, including use of commercials, billboards, and flyers to make people aware that services exist and how they can be accessed. One young woman suggested using other youth who were currently in, or had successfully made it through, the mental health, substance abuse, or juvenile justice systems as guest speakers to reach students (middle school was seen as a good starting point) about choices, options, and real-life consequences.

Service planners were urged to ***remember to include positive recreational options for youth, too.*** In one family member's words, *"It would be awesome if somehow the community could get together and provide something for teens where they could have fun, and get together with other kids their own age..."*. Youth spoke of their own positive experiences in places like the Marshall Center's recreation room.

A final suggestion came from the parent of a youth who had been in and out of jail. She advocated ***starting a youth mental health court, building on experience of the adult mental health court in Clark County.***

Provider Questionnaire Methods and Results

Provider Questionnaire methods: How we did it

More than 65 organizations that provide services to, work with, or involve youth and young adults in Clark County (see Appendix D) were mailed (or, in some instances, e-mailed) a copy of a questionnaire about youth transition (see Appendix E). Agencies were encouraged to respond via a group brainstorming process; no individual's names were attached to returned questionnaires. A business reply envelope was included, addressed to the evaluation's project manager at Portland State, so providers could return responses directly to evaluators. These providers were chosen in a snowball-type sample method and included all members of the PYT Steering Committee, all youth/young adult public mental health service providers, and additional providers recommended by Steering Committee members. We received responses from 25 organizations, including most agencies represented on the Steering Committee. Responses were entered into an Excel spreadsheet for analysis, which focused on identifying both emergent themes and unique information for inclusion in this report.

Provider Questionnaire results: What we found out

Services provided to youth of transition age

We received responses from staff at a wide range of service and support providers from throughout the county, including conventional and alternative schools, special education programs, child welfare, child and adult mental health agencies, family support and community training centers, job training centers, chemical dependency treatment centers, juvenile justice, residential treatment, adult education, and youth leadership groups. The following lists the types of services mentioned by providers. Services provided and activities engaged in include:

- Adult mental health
- Youth mental health
- Crisis intervention
- Case management
- Medication management
- Employment services/job training/job mentoring
- Chemical dependency treatment
- Juvenile justice
- Adult basic education classes
- Child Welfare
- Parent Partners
- Transition age mental health
- Family therapy
- ITC/Wraparound team
- Referral
- Alternative school/education
- Trainings
- Residential treatment
- Independent living
- Youth leadership
- Developmental Disabilities
- Youth shelter

Gaps in services

Providers presented a wide variety of services for this age group that were not provided by their agency or were unavailable, but that they would like to provide (given unlimited funding). Most often mentioned were services and supports regarding the four transition domains, especially **employment** (e.g. job training and placement, supported employment). Others mentioned that Clark County lacked services and supports for the other three transition domains: **educational opportunities** (e.g. re-entry program from students with expulsions, tours of college campuses) **community life functioning** (e.g. transportation, independent living skills training, recreation, budgeting), and **housing** (e.g. supported housing, transitional housing, personal supports for those living independently). All of these areas coincide, as was expressed by one respondent:

Housing assistance and individualized educational/vocational job training are essential.... A number of youth have left the system completely ill prepared to live independently, despite support from various systems, because they could not afford housing and other bare essentials after reaching the age of majority or after attaining a high school diploma or GED. A number of the youth turn to emergency shelters and the local plasma 'donation' center for assistance. Ideally, every youth exiting the system should have an adult whom they can count on forever. This is not always the case.

Others mentioned the **lack of specific services** provided by their particular agency or organization (e.g. evening classes, mentors) and/or **difficulty accessing services** outside the agency (e.g. could not locate recreation/transportation, respite care, family therapy, therapist for youth with dual diagnosis chemical dependency and mental health). Some providers mentioned a **lack of collaboration between multiple systems**, noting that *"One thing that is missing in the community is a mechanism for multiple systems to come together to collaborate to help youth in transition... a process that would allow multiple systems to gather on a regular basis whenever necessary. It is done now more on a case-by-case basis."* Similarly, some mentioned a **gap in long-term follow-up** after the youth leaves the program (e.g. finishing Connections and not being eligible for continued services through another agency, or graduating or leaving school and discontinuing services).

What happens when a youth reaches the age of 18 but still needs services

There is no consistent response across providers or systems for transitioning youth that reach 18 but still need services. Many respondents did not provide detailed information about what happens to a youth of transition age besides his/her services ending; for instance, one respondent wrote, *"If they have completed high school they must leave the program. What happens next is unclear, available services become very limited."* In these services, ***it may be that there is no transition planning or coordination***, or it may not have been documented for us. ***Some providers continued services through age 21 if needed or if the youth is still in school***, for example, one response stated, *"if staying, [the consumer] would continue to receive all support service assistance that was available before they turned 18 [until age 21]."* While many schools responded similarly, ***no school***

program described transition planning for a young adult reaching 21 years old who still needed services. These gaps may well be due to our unspecific questionnaire. Similarly, Juvenile Justice/Connections services end when the probation order ends, regardless of the youth's age. **A few others mentioned that their services are open to all ages**, or that services would continue with the only changes being that the youth is treated as a young adult.

A few respondents specifically **addressed transition planning in detail:**

First of all, responsible care coordination addresses needs in accordance to sensitive time frames. When we exceed age limit time frames we often follow through with 'after wrap' services to ensure that we complete assignments & tasks. We also work with other 'adult' agencies & community resources & family members on the team to help after the youth turns 18.

Transition to independent living is supported by ILS training provided through the YWCA ILS Program, by hands-on training by foster parents, by parents and relatives who allow youth to live with them after they turn 18, etc. In addition, DCFS social workers refer youth for adult mental health and/or DDD services prior to their 18th birthday so that representatives from those systems can become involved in transitional planning before the youth reach the age of majority.

For some respondents, this question doesn't seem to apply in that they serve adults, 18 or 21 and older. Again, the questionnaire may not have been specific enough (in that we are still interested in how adult providers can help with youth transitioning into adult services.) However, one respondent (from a job-training agency) noted that, although they would like to, they cannot work with youth in high school to assist in transition services because funding is not provided.

Policy barriers

The most commonly mentioned service system policy barrier to serving youth of transition age was a perceived **lack of coordination between systems and agencies** at both the individual client and the system level. Some providers stated that **services are still largely fragmented and categorical, that funding is not pooled or flexible between systems** such as developmental disabilities, mental health, and special education. Some felt that **policy about collaboration or transitioning youth to other services is unclear or unpracticed:**

The process to transition youth to MH agencies is challenging and not always clear—what is written as policy doesn't seem to occur with regularity.

A few respondents wrote that **policies restricted long-term follow-up** (see the gaps in services section above). Schools said they could not follow-up with youth after graduation; juvenile justice mentioned that services end when the youth's term of probation ends. Pooled

or public funding for services to create a seamless transition was suggested as a possible remedy.

Others mentioned **policies or practices that limit which types of services can be provided** (e.g. state codes, “controlling done by a few people—not a true choice—limited options”), a **limited timeframe in which services can be provided** (e.g. 6-month extensions to provide children’s services for youth over 18), and policies that result in a **gap in services solely due to adherence in policy** (e.g. “sometimes clients approaching the age of 18 are put on ‘hold’ in their treatment... waiting for the client to meet the 18 or older age criteria...”). Two respondents mentioned that **policies may infringe on flexibility and practicality** when working with students of transition age, for example, in DCFS:

A huge system barrier is the policy prohibiting the department from allowing youth to live in their own apartments prior to the age of 18. Youth in state custody may only reside with relatives or in licensed foster homes/group care facilities

Similarly, a school-based provider responded,

It is my understanding that in my position as a job coach, I cannot talk with students about transition agencies (DDD, DVR, etc.). That gets done by IEP teachers only, even though I'm more available than them to get the student hooked up with the agency.

Many participants mentioned policies related to eligibility requirements (e.g. age, income); those comments will be addressed in the eligibility barriers section below.

Funding barriers

Regarding funding barriers for programs, most respondents mentioned a **lack of adequate, or non-existent, funding for youth transitioning into adult services**. Specific programs also mentioned a **general lack of funding and budget cutbacks** as primary barriers; similarly, some programs’ budgets are unpredictable because they are dependent on the legislative budget and change year to year. **Policy barriers that disallowed funding adult providers to work with youth, or vice-versa**, were also mentioned, as in one agency’s comment that there was “No transitional funding for adult vocational vendors to work with youth in high school.” Others mentioned the **lack of flexibility in funding services and supports**, including categorical funding limitations and the “rigid” application of service dollars. For instance, in DCFS,

Use of ILS funds provided through the department tend to be limited – either in amount or what they can be used for. If the policy was changed to allow the department to let youth live in their own apartments, a provision would be needed to allow staff to use funds to assist with that effort rather than reimburse foster parents.

It was reported that ***flexible funds are difficult to obtain***. Specific services that needed funding were mentioned—GED testing, transportation, adult vocational services for high school students, and new technologies. One respondent mentioned the ***lack of continued funding for services when a youth leaves Clark County***, stating, “*Mental health funding is quite flexible, but once the youth leaves the county the funding does not follow the youth.*”

Two agencies surveys described the ***lack of special activities because of limited funding***: “*...we have problems doing ‘extra-curricular’ activities that would aid in building relationships with our youth.*” One participant mentioned that there was a ***lack of mental health providers that accept medical coupons***. Another described the ***frustrating search for funding*** in these words: “*There's not enough time to both research funding sources and implement programs.*” One respondent mentioned the ***lack of information available to youth and caregivers regarding flexible funds***. Another mentioned the ***lack of pooled funding*** and resulting disagreements over responsibility for funding services.

Eligibility barriers

Most commonly cited as an eligibility barrier was, of course, ***age requirements***. Not only funding for services, but eligibility for the services themselves may end or begin at the ages of 18 or 21, and ***differing services have differing age and income eligibility requirements***, resulting in “*confusing eligibility criteria for mental health and other social services.*” In other cases, it may be that services could continue, but the eligibility requirements for the funding of services have changed; for example, “*...many lose TANF when they turn 18... [leaving] them without the same level of coverage/services they had previously.*” Services often have income, housing, diagnosis, and age ***eligibility requirements that may leave some of the most needy youth out***; the ‘working poor’ family may have an income too high for public services yet be unable to afford private mental health services, some programs cannot accept teens with children, and others can only serve youth older than 18 if they are still in school.

Some mentioned that ***certain eligibility barriers might directly work against youth*** that need services the most. One respondent noted, “*[that] substance abuse may disqualify them for Medicaid or even GAX, and that substance abuse is so common in this age group, is problematic.*” One respondent mentioned that ***transportation*** was a barrier to this age group. One respondent mentioned that ***insurance companies*** might disagree with providers about the need for services.

Voice of youth and caregivers

Most ***respondents believe that youth have a significant voice in planning their own services***. Agencies described their vehicles for soliciting youth input, including Individualized and Tailored Care or Wraparound team meetings, group and individual treatment, vocational interest surveys, designated staff who solicit youth’s opinions, and

workshops to educate consumers about the service system. Clark County Developmental Disabilities wrote about,

‘Self-Directed’ services.... This means that the individual and family have more control in what services they purchased. Individuals and families approve payments or bills for their services and are they key part of the planning for the make-up of their services.

A few respondents mentioned that youth have a ***voice in provider- or system-level planning***. Connections, the Community Empowerment Project, ESD 112, the Youth Commission, DCFS and others wrote that youth are involved in or invited to participate in advisory boards and strategic planning meetings. Youth were active participants in other ways as well. For instance, in DCFS youth take an active role in organizing and serving as peer mentors in various training program, and one other provider wrote that youth in the program have a self-governance structure.

Providers also believed that caregivers have a voice in planning their child’s treatment and working on provider- or system-level planning. Again, the level of involvement ranges widely, with some respondents not mentioning any formal process (“*We are very open to feedback from the family*”), others describing somewhat indirect participation (“*I send home a parent survey for parents to voice their preferences & expectations for what services they’d like me to give... I discuss parent preferences with the student,*”), to others that irregularly have family involvement in planning (“*Families are part of the planning process; many families, however, choose not to participate*”), to still others that defined a formal process (“*In wraparound team meetings facilitators actively solicit the voice of the consumer and family member at intake, service plan creation and implementation.*”). In some situations, caregivers also have ‘family support’ staff assigned to work with them who often bring the caregiver’s concerns to the provider. Beyond individual treatment, ***a few respondents mentioned that caregivers assist in system level planning*** through family advisory boards or strategic planning meetings.

Other information for the Steering Committee/additional comments

Respondents provided a wide variety of information beyond responses to the explicit questions on the survey. Three respondents reiterated the need for the steering committee to address housing, vocational services, and employment. Others discussed the importance of the services they provide to youth and the very severe issues of the youth and their inability to address many of those issues without collaboration with other systems and services. One respondent mentioned the need to involve youth as soon and as often as possible in system planning and development, and to ensure that these youth are involved “in more than token ways.” One respondent strongly emphasized the importance of using extended family members as a resource when working with youth. One respondent wrote that there needs to be “*bed space for youth who are not wards of the state... and transitional living space for youth 18-21.*”

Discussion of combined focus group and provider questionnaire results and implications for the strategic planning process

From our research, several key themes arose independently from caregivers, youth, and providers. One major barrier mentioned by all types of participants was that ***differing eligibility criteria between agencies and systems can be confusing and frustrating*** when soliciting services. This can create delays in receipt of services, lack of funding or reimbursement for services provided, lack of preventative services or early intervention, and can drain motivation to seek services when needed.

Caregivers and youth repeatedly mentioned that they wanted services that treated them as human beings, providers that visited their community, and services that addressed the TIP domains and were diverse, flexible, and individualized, but that providers would not make this possible. Providers also repeatedly mentioned that they wanted to provide services that addressed the TIP domains, and that they wanted to access multiple, diverse, and flexible services, but that they were constrained by categorical funding limitations and other funding issues. Two issues arise here: first, that ***providers and families want similar things but feel constrained by policy and funding issues***, and second, that ***staying true to key features of the TIP/TACT models (as envisioned in Clark County) will match youth and family preferences***.

Our focus groups were very limited in terms of ethnicity and gender (the youth focus groups were almost entirely white males, the caregiver focus groups were almost entirely white females.) ***Additional efforts should be made to include the views of culturally diverse youth and family members*** in determining how services for transition-aged youth should be provided.

Youth, caregivers, and providers agree: ***collaborative, coordinated services are valued and needed throughout the transition years***. The steering committee will need to focus on mechanisms for smoother, more regular coordination of services amongst providers and systems.

While services that address TIP domains exist in Clark County, caregivers, youth, and providers alike all feel that these services are difficult to discover, access, and navigate. ***Services that address key TIP transition domains need to be completely developed and fully linked***. Transition specialists should have a complete knowledge of all available services and may want to establish connections between services.

Families and youth often feel they are not truly listened to, and are sometimes even mocked. ***RESPECT is key in engaging youth and family members***.

The participation of youth and family members at all levels of planning and providing services—individual, program, and system—is essential. Most providers believe that caregivers and youth have some say in the services they receive, but many caregivers and youth in our focus groups felt like they had little or no say in their services.

Wraparound or ITC teams appeared to be one successful tool for families to feel like they had a voice in their own services. Other promising ideas for families to be a part of system planning includes the development of family and/or youth advisory boards, a structure for youth self-governance, hiring specific staff (preferably caregivers or youth themselves) to actively solicit the voice of families, and youth serving as peer mentors in training programs.

The limitations of this research should be kept in mind: the focus groups were made up of a small number of self-selected young people and adults whose experiences probably do not represent the breadth and depth of all youth with emotional or behavioral problems in Clark County; similarly, a number of youth-serving agencies and programs did not return questionnaires, and some valuable information from providers is likely absent from this report. The strengths of this research should be remembered, too: the direct involvement of youth and family members as evaluators and focus group moderators clearly made participants more comfortable in talking about their experiences, their complaints, and their visions of what services could be like. Providers were often extremely forthcoming in their responses, and provided valuable details about a wide range of barriers to quality transition services in particular.

Thus, taken as a whole, the opinions, experiences, perceptions and reports of these young people, family members, and service providers can provide useful guidance in developing a better approach to meeting the needs of transition-aged youth and their families, and to matching the aspirations of county agencies to provide high quality services. We believe this report advances this cause.

References

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- Federation of Families for Children's Mental Health and Keys for Networking, Inc. (2001). *Blamed and ashamed: The treatment experiences of youth with co-occurring substance abuse and mental health disorders and their families*. Alexandria, VA: Federation of Families for Children's Mental Health.

Appendices

Appendix A: Focus Group Recruitment Letters

Appendix B: Focus Group Consent Forms

Appendix C: Focus Group Questions

Appendix D: Nominated and Participating Providers

Appendix E: Provider Questionnaires

Appendix A: Focus Group Recruitment Letter (Caregiver version)

March 24, 2003

Dear _____

Thank you for expressing an interest in taking part in a small group discussion (or 'focus group') for the Partnerships for Youth Transition project. We are interested in your thoughts and comments about Clark County mental health services because you are a caregiver or family member of a youth (aged 14-25 years) who is receiving, or has received, mental health services and is transitioning, or has transitioned, into adulthood. Sharing your experiences and thoughts will help the project improve the quality of services for transition-aged youth and their families.

The focus groups gather information from families about their experiences with services in Clark County for their child's needs, especially as they relate to transitioning into adulthood. We want to find out which issues matter the most to you and your family. This information will be shared with the Steering Committee of the Partnerships for Youth Transition project to help them develop high-quality services.

Focus groups will be conducted by staff from the Regional Research Institute for Human Services at Portland State University, together with youth and caregivers in Clark County and the Steering Committee. Each group will have five to eight other caregivers of transition-aged youth. You will be asked to discuss a series of questions about the needs and experiences of families with youth in transition. With everyone's agreement, the discussions will be tape recorded, so we can be sure to report your opinions accurately. Groups will take between an hour and an hour and a half, and you will be given a \$15 gift certificate for your time. If needed, you will be reimbursed for childcare costs and/or taxi fare as well.

The types of questions that you'll be asked include:

1. What services and supports are helpful to your child and family?
2. What services and supports are not (or were not) or needed by your child and family?
3. What kind of say have you had in deciding the services and supports your son or daughter, or your family, receives?
4. How could Clark County improve its mental health and other services to families with youth of transition age?

Only the other group members and moderators, along with researchers at the Regional Research Institute, will hear your individual responses. As the enclosed informed consent document describes, special care will be taken to keep your identity and information private. The only exception is if researchers learn of, or have good reason to suspect, that child or elder abuse has occurred or there is imminent danger of harm.

Taking part in a focus group is completely voluntary. You can choose to not answer any question, or you may leave the group at any time. If you choose not to participate, it will not affect your relationship with Clark County, your service providers, or the Regional Research Institute. If you decide to take part, you'll be asked to sign a copy of the enclosed informed consent form at the time of the focus group itself. As you tentatively agreed when you spoke with Diana Burger or myself, your focus group will meet on _____, from _____ to _____, at _____. If you've decided to take part, please confirm by calling Diana at 397-2130 x7839. If you can't make this focus group, please let Diana know as far in advance as possible, so someone else can take your place.

Thanks again,

DeDe Sieler, Partnerships for Youth Transition Project Manager

Appendix A: Focus Group Recruitment Letter (Youth version)

March 24, 2003

Dear _____

Thanks for expressing an interest in taking part in a focus group for the Partnerships for Youth Transitions project. We are interested in your thoughts and comments about Clark County mental health services because you've received mental health services and are near the age of transitioning into adulthood (ages 14-25). Sharing your experiences and thoughts will help the project improve the quality of services for transition-aged youth and their families.

The focus groups gather information from youth about their experiences with services in Clark County, especially as they relate to transitioning into adulthood. We want to find out which issues matter the most to you, your peers, and your family. This information will be shared with the Steering Committee of the Partnerships for Youth Transition project to help them develop high-quality services.

Youth focus groups will be conducted by two youth facilitators from the Regional Research Institute for Human Services at Portland State University, together with youth and caregivers in Clark County and the Steering Committee. Each group will have five to eight other transition-aged youth. You will be asked to discuss a series of questions about the needs and experiences of youth in transition. Groups will take between 60 and 90 minutes, and you will be given a \$15 gift certificate for your time (we'll feed you, too!). If everyone present agrees, your group will be tape recorded, so we can report your ideas accurately. All tapes will be erased after a report to the Steering Committee is completed.

The types of questions that you'll be asked include:

5. What services and supports are (or were) helpful to you?
6. What services and supports are not (or were not) helpful?
7. What kind of say have you had in deciding the services and supports you get?
8. How could Clark County improve its mental health and other services to youth of transition age?

Only the other group members, the youth moderators, and researchers at the Regional Research Institute will hear your comments from the group itself. As the enclosed informed consent document describes, special care will be taken to keep your identity and information private. The only exception is if researchers learn that someone's hurt you, that you've hurt (or plan to hurt) someone else, or if a senior citizen has been hurt by someone.

Taking part in a focus group is completely voluntary. You can choose to not answer any question, or you may leave the group at any time. If you choose not to participate, it will not affect your relationship with Clark County, your service providers, or the Regional Research Institute. If you decide to take part, you'll be asked to sign a copy of the enclosed informed consent form at the time of the focus group itself. As you tentatively agreed when you spoke with Diana Burger or myself, your focus group will meet on _____, from _____ to _____, at _____. If you've decided to take part, please confirm by calling Diana at 397-2130 x7839. If you can't make this focus group, please let Diana know as far in advance as possible, so someone else can take your place.

Thanks again,

DeDe Sieler, Partnerships for Youth Transition Project Manager

Appendix B: Focus Group Consent Form (Caregiver version; not to scale)

Partnerships for Youth Transition

Focus Group Informed Consent Form—Caregiver/Family Member

You are invited to participate in a focus group for the Partnerships for Youth Transition project. We are interested in your thoughts and comments about the mental health services in Clark County because you are a caregiver or family member of a youth who is receiving (or has received) mental health services and who is transitioning into adulthood. Sharing your opinions will help the project improve the quality of services for transition-aged youth and their families.

Who is doing this?

The Regional Research Institute for Human Services at Portland State University, together with youth and caregivers in Clark County and the Steering Committee of the Partnerships for Youth Transition project.

Why is it being done?

The focus groups gather ideas from families about their experiences with services in Clark County for their child's needs, especially as they relate to transitioning into adulthood. We want to find out which issues matter the most to you and your family. This information will be shared with the Steering Committee to assist them in developing high-quality services.

What's involved?

One family member researcher and one staff researcher on our project will conduct the focus groups. Each group will have five to eight other caregivers of transition-age youth. You will be asked to discuss a series of questions about the needs and experiences of families with youth in transition. Groups will take between an hour and an hour and a half. If everyone agrees, the discussions will be tape recorded, because we want to be sure to report your opinions accurately. No one will be identified by name in any report, however, and the tapes will be erased afterwards. You will be given a \$15 gift certificate for your time. If needed, you will be reimbursed for child care costs as well.

The types of questions that you'll be asked include:

1. What services and supports are helpful to your child and family?
2. What services and supports are not (or were not) useful or needed by your child and family?
3. What kind of say have you had in deciding the services and supports your son or daughter, or your family, receives?
4. How could Clark County improve its mental health and other services to families with youth of transition age?

Who gets to hear what I say?

Only the other focus group members and moderators, along with staff researchers at the Regional Research Institute, will hear what you have to say in the groups. We will not share your individual responses with anyone else. We will prepare a report that mixes your responses with other group members' ideas. This summary of feedback and themes will be shared with the Steering Committee.

How am I protected?

There is always some risk involved with participating in a research project, but we will take all precautions to protect you from this risk. One risk is that you might feel uncomfortable thinking and talking about your experience as a family member of a youth with mental health problems. You may also feel uncomfortable talking about the service providers you have encountered. To protect you, we have included the name and phone number of someone you can contact if you need to talk about your experience in the focus groups.

Another risk is that someone taking part in the focus group could later tell people outside the group what you said. To protect you from this risk, everyone who takes part is asked –and reminded—that the group discussion is to be kept private.

A final risk is that someone could figure out that you'd taken part in a focus group, and would try to get back at you for what you said. We do the following things to protect the privacy of your responses:

- During the focus group, you can choose to use a nickname (or 'pseudonym') to hide your identity.
- When we're preparing our report, only a code, not your name, will be used to identify your personal ideas.
- When we give our report to the Steering Committee, your answers will be mixed together with the answers of other focus group members. No record of your name will be kept.
- Audiotapes of the focus groups will be summarized, then erased within two weeks of the focus group.

By law, we must report to the authorities if we learn that physical or sexual abuse of a child or elderly person has occurred or that there is imminent danger of harm.

Do I have to do this?

No. The focus group is voluntary. You can choose not to answer any questions. You may leave the group at any time. If you choose not to participate, it will not affect your relationship with Clark County, your service providers, or the Regional Research Institute.

A copy of this consent form will be provided to you.

By signing below, you agree to take part in a focus group. You understand that all information will be kept confidential to the extent permitted by law. You certify that you have read this consent form or it has been read to you.

Your signature

Please print your name

Date

Consent to audiotaping

By signing below, you agree to have your comments tape recorded. You understand that your real name will not be connected to anything you have to say. You know that the tapes will be erased after a report to the Project Steering Committee has been prepared.

Your signature

Please print your name

Date

Moderator's signature

Moderator's printed name

Date

If you have questions about the focus groups, call Lyn Gordon, Project Manager, at the Regional Research Institute, 503-725-4114. You can also e-mail him at gordonl@pdx.edu.

If you have other concerns or experience problems as a result of your participation in this study, please contact the Human Subjects Research Review Committee, Office of Research and Sponsored Projects, 111 Cramer Hall, Portland State University, 503-725-8182.

Appendix B: Focus Group Consent Form (Youth version; not to scale)

Partnerships for Youth Transition

Focus Group Informed Consent Form—Youth

You are invited to take part in a small group discussion (or ‘focus group’) for the Partnerships for Youth Transition Project. We are interested in hearing your comments about mental health services in Clark County because you have received mental health services and are near the age of transitioning into adulthood. Sharing your experiences and opinions will help the project improve the quality of services for transition-aged youth and their families.

Who is doing this?

The Regional Research Institute for Human Services at Portland State University, along with Clark County youth and caregivers and the Steering Committee of the Partnerships for Youth Transition project.

Why is it being done?

The focus groups give youth a chance to talk about their experiences with mental health, juvenile justice, drug and alcohol treatment, special education and other services in Clark County. We are especially interested in how youth are supported (or not) as they transition into adulthood. We want to find out which issues matter the most to you, your peers, and your family. Your ideas will be shared with the Steering Committee to help them develop high-quality services.

What’s involved?

Youth researchers on our project will conduct the focus groups. Each group will have five to eight other youth. You will be asked to discuss a series of questions about the needs and experiences of youth in transition. Groups will take between 60 to 90 minutes. You will be given a \$15 gift certificate for your time. If everyone agrees, groups will be tape recorded, because we want to be sure we report your ideas accurately. However, all tapes will be erased after a report to the Steering Committee is prepared.

What will you ask me?

The types of questions that you’ll be asked include:

- What services and supports are (or were) helpful to you?
- What services and supports are not (or were not) helpful?
- What kind of say have you had in deciding what kinds of services and supports you get?
- How could Clark County improve its mental health and other services to youth of transition age?

Who gets to hear what I have to say?

Only the other focus group members and youth moderators, along with researchers at the Regional Research Institute, will hear your comments from the focus group itself. We will not share your individual responses with anyone else. We will prepare a report that mixes your responses with other group members’ ideas. This summary of feedback and themes will be shared with the Project Steering Committee.

How am I protected?

There is always some risk involved with participating in a research project. We will take steps to protect you from this risk. One risk is that you might feel uncomfortable thinking and talking about your experiences. You may also feel uncomfortable talking about the service providers you have encountered. To protect you, we have included the name and phone number of someone you can contact if you need to talk about your experience in the focus groups.

Another risk is that someone taking part in the focus group could later tell people outside the group what you said. To protect you from this risk, everyone who takes part is asked –and reminded– that the group discussion is to be kept private.

A final risk is that someone could figure out that you'd taken part in a focus group, and would try to get back at you for what you said. We also do the following things to protect your privacy of your responses:

- During the focus group, you can choose to use a nickname (or 'pseudonym') to hide your identity.
- When we're preparing our report, only a code, not your name, will be used to identify your personal ideas.
- When we give our report to the Steering Committee, your answers will be mixed together with the answers of other focus group members. No record of your name will be kept.
- Audiotapes of the focus groups will be summarized, then erased within two weeks of the focus group.

By law, we must report to the authorities if we learn that someone's hurt you, that you've hurt (or plan to hurt) someone else, or if someone has hurt a senior citizen.

Do I have to do this?

No. The focus group is voluntary. You can choose not to answer any questions. You may leave the group at any time. If you choose not to take part, it will not affect your relationship with Clark County, your service providers, or the Regional Research Institute.

A copy of this consent form will be provided to you.

By signing below, you agree to take part in a focus group. You understand that all information will be kept confidential to the extent permitted by law. You certify that you have read this consent form or it has been read to you.

Your signature

please print your name

Date

Consent to audio taping

By signing below, you agree to have your comments tape-recorded. You understand that your real name will not be connected to anything you have to say. You know that the tapes will be erased after a report to the Project Steering Committee has been prepared.

Your signature

please print your name

Date

Moderator's signature

Moderator's printed name

Date

If you have questions about the focus groups, call Lyn Gordon, Project Manager, at the Regional Research Institute, 503-725-4114. You can also e-mail him at gordonl@pdx.edu.

If you have other concerns or experience problems because you took part in this study, please contact the Human Subjects Research Review Committee, Office of Research and Sponsored Projects, 111 Cramer Hall, Portland State University, 503-725-8182.

Appendix C: Focus Group Questions (Caregiver version)

PARTNERSHIPS FOR YOUTH TRANSITION PROJECT QUESTIONS FOR FAMILY MEMBER FOCUS GROUPS

Services your child is (or has been) involved with: _____

Helpful services or supports

What services or supports are helpful to your child and/or family, or were helpful in the past?

What makes these services or supports especially helpful?

Problems with services

What services for youth are not useful or needed?

What barriers or brick walls have you come up against in the service system in the last month? Ever?

If you could change one thing to make it easier, what would it be?

Having a say in services

Do you (or did you) have a voice, a say in influencing your child's service planning and delivery?

Are you (or were you) taken seriously? Why or why not?

Appendix C: Focus Group Questions (youth version)

PARTNERSHIPS FOR YOUTH TRANSITION PROJECT QUESTIONS FOR YOUTH FOCUS GROUPS

Age: ____ Services you are (or have been) involved in: _____

Helpful services or supports

What services or supports are helpful to you, or were helpful to you in the past?

What makes these services or supports especially helpful?

Problems with services

What services for youth are not useful or needed?

What barriers or brick walls have you come up against in the service system in the last month? Ever?

If you could change one thing to make it easier, what would it be?

Having a say in services

Do you (or did you) have a voice, a say in influencing your service planning and delivery?

Are you (or were you) taken seriously? Why or why not?

Appendix D: Nominated and Participating Providers

Agency/Provider that received questionnaire (via mail or e-mail)	√ = Questionnaire Returned
❖ <u>All Steering Committee Members (Individual and Agency Representation)</u>	
• Division of Developmental Disabilities	√
• Clark County Juvenile Services/Connections	√
• Department of Child and Family Services	√
• ILS/YWCA	
• Mental Health NW	√
• Catholic Community Services	√
• FirGrove/Vista	√
• CRMHS	√
• Clearview	
• DCS Developmental Disabilities	√
• Janus Youth Programs	√
• DCS Drug & Alcohol	
❖ RSN Care Management team	
❖ Recovery NW	√
❖ Parent Partner Program	√
❖ Clark County Health Department/Teen Clinic	
❖ Clark College	
• Mary Deal/Career Center/Financial Aid/GED program	√
❖ WSU Career Center/Financial Aid	
❖ ESD 112 Workforce	√
❖ GAP	
❖ North County Family Resource Center	
❖ Department of Vocational Rehabilitation	
❖ Ombudsman	
❖ Evergreen Inn	
❖ Citizens Voices Are Born	
❖ Community Empowerment Program	√
❖ Children's Center	
❖ Children's Home Society	
❖ Battle Ground SD Special Services	√
❖ Camas SD Special Services	
❖ ESD 112 Direct Services Division	√
❖ Evergreen SD Special Services	
❖ Vancouver SD Special Services	

❖ Washougal SD Special Services	√
❖ Center for Dual Diagnosis/CRMHS	
❖ CDAC (Community Drug and Alcohol Center)	
❖ Daybreak (Inpatient treatment)	
❖ Kaiser Permanente Dept. of Addiction Medicine	√
❖ Northwest Counseling Associates (Drug/Alcohol)	
❖ Northwest Deaf Addiction Center/Pacific Crest Consortium	
❖ The Right Choice (Drug/Alcohol)	
❖ Western Psychological and Counseling Services	
❖ YMCA	
❖ Hudson's Bay "I Have a Dream" program	
❖ Juvenile Rehabilitation	
❖ Hudson's Bay Magnet Career Mentoring	
❖ Hudson's Bay Teen Parent Program	
❖ Community Resource Mentors	
❖ 4-H Juvenile Justice Community Service Club	
❖ Clark County Youth Commission	√
❖ YLEAD	
❖ Evergreen H.S. Prevention/Intervention Specialist (R.B.)	
❖ Employers Overload	
❖ Goldman & Associates, Inc.	
❖ Keys to Advancement	
❖ Mission Possible	
❖ Nelson & Associates	
❖ SEH America	
❖ STEPS to the Future	√
❖ Legacy H.S./Evergreen SD	√
❖ Lewis & Clark H.S./Vancouver SD	
❖ Summit View H.S./Battle Ground SD	
❖ ESD 112 Youth Services/Credit Recovery Program	
❖ ESD 112 Truancy Program	
❖ NAMI	
❖ WorkSource/Private Industry Council	
❖ Elahan Place	√
❖ The Encore Group NW	√

Appendix E: Provider Questionnaires

Partnerships for Youth Transition Project

Thank you for agreeing to complete this questionnaire. We're gathering information on the services provided to youth (ages 14-25) with emotional or behavioral difficulties who are transitioning into adulthood, the barriers to providing those services, and the participation of youth and caregivers in planning those services. This research is part of the Partnerships for Youth Transition project planning process, and your responses will help influence the design and delivery of high quality transition services and supports for young people in Clark County. Your participation is completely voluntary. Your name is not required. If you choose not to participate, it will not affect your relationship in any way with the Partnerships for Youth Transition Steering Committee, Portland State University, or the Clark County Department of Community Services.

Because it is essential for the planning process, any information you provide will be shared with the Steering Committee of the Partnerships for Youth Transition project. This committee includes representatives of the Clark County Department of Community Services and Corrections, mental health providers, schools, the YWCA, the Division of Child and Family Services, residential services providers, GED/Dept of Vocational Rehabilitation, and youth and family consumers. Thanks again for your help! Please return to: Lyn Gordon, Regional Research Institute, Portland State University, P.O. Box 751, Portland, OR 97207-0751; e-mail: gordonl@pdx.edu

1. Agency or provider site where this questionnaire was completed:
2. Please describe all of the services your agency provides to transition age youth (and their families or caregivers, if applicable):
 - Which services are missing or not available but you would like to provide (if adequate funding was available)?
3. Please describe **service system policy barriers** to serving transition age youth:
4. Please describe **service system funding barriers** to serving transition age youth:

5. Please describe **service system eligibility barriers** to serving transition age youth:
6. Please describe how your agency incorporates the voice of transition age youth in planning and delivering services to themselves or other youth:
7. Please describe how your agency incorporates the voice of family members or caregivers of transition age youth in planning and delivering services:
8. Please tell us what happens if a youth in your agency reaches the age of 18 but still needs services:
9. Is there anything else the Steering Committee should know in order to develop a program that will meet the needs of Clark County youth as they transition into adulthood (please use the attached blank sheet for additional comments)?

Additional comments in response to any question: